



by Kathy Harris

Guardianship is Not Self-Determination

Guardianship is created so that one person can take over the decisions of another -- another who has been determined to be incapable of making decisions for him/her self. This imposition is the total antithesis of self-determination principles. Although some still see guardianship as having a benevolent purpose, we must:

[r]ecognize guardianship for what it really is: the most intrusive, non-interest serving, impersonal legal device known and available to us and, as such, one which minimizes personal autonomy and respect for the individual, has a high potential for doing harm and raises at best a questionable benefit/burden ratio. As such, it is a device to be studiously avoided.¹

Claude Pepper, U.S. Representative from Florida in the 70's, and a champion of the rights of older people, made the following statement in a study of guardianship conducted by the Pepper Commission:

"The typical ward has fewer rights than the typical convicted felon. They no longer receive money or pay their bills. They cannot marry or divorce ... It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception ... of the death penalty."²

Guardianship frequently removes constitutional rights of individuals. Over thirty states have statutes that deny the right to people under guardianship to marry or vote. The simplest of decisions that we all take for granted can be taken away from the individual and given to another under guardianship. This includes the right to decide where we want to live, what kind of work we may wish to pursue, where we'd

like to travel, how we'd like to spend our money, even who we want to spend our time with.

Some providers of services for individuals with labels of developmental disabilities have requested that families or friends seek courtappointed

guardianship because the providers believe it is a legal necessity. In fact, there is generally no legal requirement that if a person needs assistance with decision-making, that the person who acts as a surrogate decision-maker must be a legal guardian. Providers are often not familiar with alternatives, and thus do not promote the use of support circles, family consent policies, powers of attorneys, trusts, and other alternative surrogate decision-making devices.

Support circles which function through a person-centered process are an important key to avoiding guardianship. We all have friends, family and others who we call upon when we need help or advice when making life decisions. When we need to make decisions about health care, finances, or where to live, we ask knowledgeable people who make up our "support circle" to help us make these decisions. These people we call upon for help do not file to become our guardians, even though we may be incapable of making good decisions without their help.

Individuals with developmental disabilities need the same kind of support circles to help make decisions. This decision making process is essential to living the self-determined life we all enjoy. When called upon to write a "plan" for someone's life, we first must determine what the individuals themselves desire for their own lives. If individuals aren't able to communicate their desires for any reason, their family, friends, and others close to them can help to determine their wishes. They do this by using their knowledge about the individual and how they communicate. This includes their observations about the individual's behavior including facial expressions, gestures, and sounds that indicate their

preferences. In this way, the support circle can arrange medical treatment, help at the school IEP, or gain supports from community programs that will help the individual with a disability find a place to live or get a job.

There are cases in which individuals do not have family or friends in their lives to act as a support circle. This calls for creative development of ways to bring community members into these individuals' lives so that over time a support circle will develop, thus negating the need for guardianship.

When such a support system is in place, there is no need for a legal guardian to make decisions for the individual. In fact, imposing guardians on individuals could interfere with the support circle process. If there is a court-ordered guardian, there is a danger that one person may be allowed to impose their decisions on the individual without the benefit of knowing what the person desires, either directly or through the observations of the support circle.

Courts around the country have begun to recognize that outside supports for an individual may negate the need for guardianship. In Iowa, the Supreme Court there has stated, "In making a determination as to whether a guardianship should be established ... the court must consider the availability of third party assistance to meet a ... proposed ward's need for such necessities."³

The Pennsylvania Supreme Court stated, "Persons cannot be deemed incapacitated if their impairments are counter-balanced by friends, family or other support."⁴

And Tom Nerney, Executive Director of the Center for Self-Determination, has stated, "We have to reject the very idea of incompetence. We need to replace it with the idea of 'assisted competence.' This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights."⁵

Through self-determination, with the use of a person-centered planning process,

guardianship can be avoided. This would be to the advantage of the individual, who retains his/her decision-making rights, and to the community that reaps the benefit of total inclusion of all of its citizens.

Those who followed the Terry Schiavo case in Florida this past year have found good reason for alarm about the direction of our society for people with intellectual disabilities. Most states now recognize that individuals have a “right” to determine their wishes through living wills and patient advocate forms, and can give directions about removing life-sustaining procedures.

What about people who have been determined “incompetent” by a court of law, thus unable to make such decisions for themselves? Such decision-making ability is given to guardians, who are charged with making decisions in the person’s “best interests.” Given that people who have been adjudicated “incompetent” have historically faced a loss of status, rights, and value, it has become acceptable to determine that death is preferable to living with a disability.

A change is needed to raise awareness of the value of people with disabilities as equal to those without disabilities. It is essential that the idea of making decisions in the “best interest” of individuals be replaced by families, friends, and those close to people with intellectual disabilities willing to go through the work of ascertaining the individual’s preferences and dreams. Only in this way will people with disabilities attain true equality and overcome the enormous prejudice against them.

Other alternative methods to handle decision-making also may be useful. Most states have family consent statutes, or their health care providers have family consent policies. These statutes and policies allow family members or others who are close to the individual to make medical decisions in the event individuals cannot make the decision for themselves. Providers of other kinds of services and supports also have such policies and recognize that there is no reason to have legal guardianship imposed as long as a family member or other close person is involved in the person’s life and can arrange needed services. If your state does not have a family consent statute, or if providers are not aware that they may implement such policies, they need to be informed of this simple and effective alternative to guardianship. More often, the statutes or policies exist, but are not used.

Another device that may prove useful is the use of durable powers of attorney. These are documents that can be used by an individual to designate another person to discuss and make decisions about medical decisions, living situations, confidentiality issues and other areas of concern. In this way, family members or others who have always assisted the individual in making such decisions can continue to do so without filing a petition to become guardian. The power of attorney allows the individual to give that power to someone, and they can also take away that power if they become unhappy with the decisions being made.

When money is involved, there are other alternatives. If an individual is the recipient of public benefits and is unable to handle the funds, a representative payee can be appointed. This is someone who receives and disburses the money for the individual. If a parent wants to provide for their son or daughter with a disability after the parents’ death, or if a substantial amount of money comes into an individual’s life, amenities trusts, also known as special needs trusts, can be devised. These kinds of trusts appoint a trustee to handle the funds without interfering with the individual’s Medicaid benefits. Additionally, such trusts can specify that someone visit the individual to assure they are satisfied with his/her living situation and support systems. This is more than the imposition of a guardian or conservator can do for an individual, and gives more peace of mind to parents who worry about what will happen to their son or daughter when they are gone. A knowledgeable attorney should be consulted about these trust documents.

Educational programs about these kinds of alternatives need to be implemented for families, professionals and advocates. Putting an end to the systematic removal of rights and concomitant removal of protections for people with disabilities needs to be a priority. This means a different way of doing business. Those who care about an individual with a disability and those who make their living because of individuals with disabilities, have an obligation to discover what people like and don’t like, what their desires and preferences are. We

should employ the many alternatives which currently allow people to avoid guardianship altogether. Ultimately, we can use the framework of person-centered planning and self-determination to obtain the optimum choice making. We can assure individuals with disabilities, including those with cognitive disabilities and those who communicate using alternative methods, access to life, liberty and the pursuit of happiness. In so doing, we will have eliminated an unnecessary barrier to individuals' opportunity to seek their piece of the American dream.

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- 3 In the Matter of Hedin, 1995, Iowa Supr. Ct.
- 4 In Re: Perry, 727 A2d 539, (Pa. Supr. Ct., 1999)
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